



# FALL

## **ARKANSAS NEWBORN SCREENING NEWSLETTER VOLUME 1, ISSUE 3**

### **The Role of the UAMS/ACH**

**Newborn Screening Coordinator, by Jason Ketcher, RN, BSN**

With the expansion of newborn screening in 2008, the role of Newborn Screening Coordinator (NBS Coordinator) was created within the University of Arkansas for Medical Sciences (UAMS) section of Pediatric Genetics which is housed at Arkansas Children's Hospital (ACH). Due to the critical nature of newborn screening, there is need for prompt communication among the ADH NBS program nurses, ACH medical specialists, and pediatric providers. The NBS Coordinator serves a vital role as liaison in linking services and providers to assure babies with positive results are evaluated rapidly and followed.

ACH performs second tier screenings on initial abnormal NBS results for cystic fibrosis and congenital adrenal hyperplasia; two disorders where a second, more definitive screen helps assess the likelihood of a true disorder and need for further evaluations. The NBS Coordinator follows the second tier tests and communicates results to the ADH NBS program and pediatric specialists. Also, babies with abnormal newborn screens are often referred to ACH for evaluation. The NBS Coordinator arranges expedited visits with pediatric geneticists and other specialists who determine diagnoses and treatment plans; and then works with ADH NBS nurses to assure follow-up and treatment.

Another key function of the NBS Coordinator is to arrange sweat testing for babies identified as having changes in the CFTR gene on the second tier test for cystic fibrosis. The coordinator provides support to families before, during and after the test. After sweat testing, the NBS Coordinator discusses results; and for infants diagnosed with either cystic fibrosis or cystic fibrosis related metabolic syndrome (CRMS), the family also meets with a genetic counselor. The infant is immediately referred to Pediatric Pulmonology, often the same day as the sweat test.

These are just a few of the many responsibilities for the UAMS/ACH NBS Coordinator.

You may contact Jason at 501-364-4050 or e-mail: [jmketcher@uams.edu](mailto:jmketcher@uams.edu).

## **LAB NOTES BY: LESLIE HIMSTEDT**

**“Rules and Regulations Pertaining to Testing Newborn Infants” specifies that specimens shall be submitted to the lab within 48 hours of collection. Currently, only 13% of the samples submitted statewide reach the lab within this timeframe. Prompt specimen delivery to the lab is CRITICAL. Due to the nature of some of the disorders for which we screen, it is imperative that the samples be sent to the lab on a DAILY basis and NOT BATCHED for submission. Affected babies must be identified quickly so diagnostic testing and treatment may begin as soon as possible.**

**Samples must be packaged in an appropriately sized paper envelope. Do not fold the cards and do not place in a plastic bag. It is strongly recommended that the packages be taken to the local county health unit for delivery on their overnight courier. Contact your local county health unit for approximate pick up times.**

**Leslie**

## **NURSING NOTES: MARY JEAN GRESHAM, RN**

**Having finished all my out of town hospital visits, I’m thrilled to note that 20 of those, out of 37 hospitals, are now using the local health unit couriers for their specimen submissions. The number of specimens, arriving late, has dropped and hopefully will keep going down.**

**We now have a “tool-kit” that every hospital will receive when I make my site visit. It includes a list of informational websites, the disorders we screen, a copy of the state’s Rules & Regulations for doing the newborn screen and also a booklet of the approved standards by Clinical and Laboratory Standards Institute. Two more posters are included, featuring collection technique and pictures of unacceptable specimens. A DVD, formulated in conjunction with ACH and UAMS, demonstrating the collection procedure is also included. As other information arises we will send it along to the hospitals to be added to this tool-kit. We are also going to put the tool-kit materials on our website.**

**Our unsatisfactory specimen numbers, statewide, has risen this year. There were only 77 specimens rejected last year and the number is already 130 for 2013. Thirty-eight of these rejections have been due to late mail delivery of the specimens to the state lab and only 25 of these have been repeated. This means at least 13 babies have not had a newborn screen, this year. If you are in question concerning the appearance and validity of your specimen, please refer to your poster, which shows pictures of acceptable and unacceptable blood spot specimens. Contact us if you do not have your old posters, otherwise, I will bring new ones with my next visit.**

**Mary Jean Gresham, RN**



***Congratulations to St. Vincent Infirmary in Little Rock for being “Most Improved” in sample delivery times this quarter!***

***Newborn Screening video now available on our website and on DVD!***

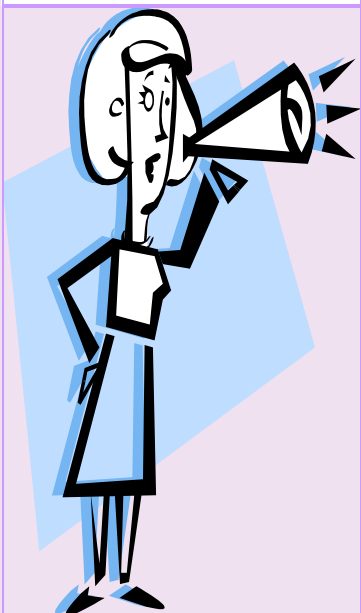
***<http://www.healthy.arkansas.gov>***

- 1). Click on Programs and Services
- 2). Click on Child and Adolescent Health
- 3). Click on Newborn Screening (on the left)
- 4). Click on Health Professionals (on the left)
- 5). Scroll down to Downloads and Information

***Please use the video for orientation and updates for your nursery staff. It is based on national standards for blood spot specimen collection.***

***Mary Jean will also be bringing nurseries a DVD on her next site visit to your hospital. If you want a DVD before her scheduled visit, just give her a call:***

***Mary Jean Gresham, RN (501) 280-4774.***



**\*\*\*ALL STATE OFFICES WILL BE CLOSED NOVEMBER 28th AND 29TH\*\*\***

